

**Mothers' Psychosocial Adaptation to Cancer:
The Role of Mutuality and Support
in the Primary Partnered Relationship**

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Statement of the Research Problem

Each year, thousands of women are diagnosed with cancer. According to the American Cancer Society (1996), nearly one in three women will develop cancer in her lifetime, and nearly one in four will die from the disease. In 1996 alone, it was estimated that 594,850 women would be diagnosed with some form of invasive cancer, and that 262,440 of these women would die of the disease (American Cancer Society, 1996). Recent data also show that cancer is the leading cause of death among women ages 35 to 54, and is the second cause of death among women in the United States (American Cancer Society, 1992). Subsequent to increases in both the prevalence of cancer and patient survival time, it has become increasingly important to understand how people cope and live with cancer. This research examines the impact of women's primary partnered relationships on their psychosocial adaptation to the diagnosis and treatment of cancer.

Research and practice have demonstrated that a diagnosis of cancer is generally accompanied by any number of psychosocial sequelae for adult men and women including anxiety and depression (Dean, 1988), uncertainty, loss, and confusion about one's sense of identity and purpose (Anderson, 1991; Barnard, 1990), sexual problems (Roth & Robinson, 1992), fear of death (Roth & Robinson, 1992), marital and family disruption (Hough, Lewis, & Woods, 1991; Overholser & Fritz, 1991), and social and work disruption for both patients and their loved ones (DesRosier, Catanzaro & Piller, 1992; White, Richter & Fry, 1992). Several psychosocial consequences specific to women coping with cancer and other chronic illnesses have also been identified. Examples include diminished or depleted sense of self and femininity in women diagnosed with breast or gynecologic cancers; loss of purpose if infertility is a side effect of treatment (Roth & Robinson, 1992); and numerous fears and concerns about their children's well being from mothers struggling to maintain their caregiving roles and responsibilities while coping with a chronic illness (Thorne, 1990).

Research has yielded several additional consistent findings which are also significant here. For example: social support is an important resource for individuals coping with illness (Bartels, Desrossier, Cantanzaro, & Piller, 1992; Mishel & Braden, 1987; White, Richter & Fry, 1992); the quality of supportive relationships as well as the quantity is important (Hough,

Lewis & Woods, 1991; House & Kahn, 1985; Pearlin et al., 1981); intimate relationships are perhaps the best transmitters of support (Hobfoll & Walfisch, 1984; Mishel & Braden, 1987; Peters-Golden, 1982); and of one's intimate relationships, the spousal relationship is perhaps the most significant (Bartels, DesRosier, Cantanzano, & Piller, 1992; Charmaz, 1983; Hough, Lewis & Woods, 1991; Lewis, Woods, Hough & Bensley, 1989; Lin, 1986; Pearlin et al., 1981; Wills, 1983). These data offered additional justification for this exploration on the ways in which women's primary partnered relationships may help or hinder their successful adaptation to the diagnosis and treatment of cancer.

Despite these findings, the psychosocial literature has provided limited empirical exploration of gender differences in coping with chronic illness or the potentially unique problems and issues of women (Kline-Leidy, 1990). Rather, women's responses to stressful life events such as a diagnosis of cancer are examined, assessed, and subsequently treated through the conceptual lens of developmental theories based on male subjects and male experience. In an attempt to address the theoretical weaknesses of previous studies, the framework for this study emanated from theories of women's psychological development which have emerged since the 1970s. Examples of these theories include work on moral reasoning (Gilligan, 1982; Taylor, Gilligan & Sullivan, 1996); research on women's cognitive styles (Belenky, Clinchy, Golderberger & Tarule, 1986); theories on women's social development (Jordan, Kaplan, Miller, Stiver & Surrey, 1991); and research on women's relationship schemas (Jack, 1990). All of these theories emphasize the pivotal significance of women's relationships in their lives and in their conceptions of self.

Self-in-relation theory, which was developed by Jean Baker Miller and her colleagues at the Stone Center in Wellesley, Massachusetts, was particularly important in this research. According to this theory, a woman's sense of self is conceptualized as "being in relation" and the pursuit and development of mutually empathic relationships is a basic and significant goal of a woman's psychological growth. This theory was developed as an attempt to counter the traditional framework which used male experience as the benchmark for normalcy and subsequently depicted women as unhealthy and deficient.

Research Questions

Utilizing a relational perspective, this research was founded on the belief that, in order to understand women's coping processes, it is important to understand how they think, feel, and act in their relationships during the illness experience. Subsequently, a model was developed to examine these components of women's relationships and to examine the following set of four hypotheses:

1. The level of mutuality in women's primary partnered relationships will be positively correlated with the level of cancer demands they experience.
2. Women whose primary partnered relationships are characterized by higher mutuality are more likely to use the coping strategy of active engagement than women whose primary partnered relationships are characterized by lower mutuality.
3. Women whose primary partnered relationships are characterized by lower mutuality are more likely to use the coping strategy of protective buffering than women whose primary partnered relationships are characterized by higher mutuality.
4. The level of mutuality in women's primary partnered relationships will be positively correlated to their psychosocial outcome.

The first concept in the model is **relationship mutuality**, and refers to a person's perception of the exchange of feelings, thoughts, and activities she has with a significant other. This variable was measured with the Mutual Psychological Development Questionnaire (MPDQ), a 22-item measure of bi-directional movement of feelings, thoughts, and activity between persons in relationships. Respondents use a 6-point Likert-type scale to rate a relationship from both their own perspective and that of the other person involved in the relationship. In the present study, "significant other" refers to the respondent's primary partner. An initial study by Genero, Miller, Surrey, and Baldwin (1992) demonstrated high inter-item reliability, construct, and concurrent validity.

The second concept in the model is **demands of illness** and refers to the demands associated with the diagnosis and treatment of cancer. This variable was measured with a subscale of the Demands of Illness Inventory (DOII) (Packard, Haberman, Woods & Yates, 1991) which is designed to assess illness-related cognitions and events that individuals experience in response to health problems. Items measure the frequency and perceived intensity with which illness-related demands occur in both the acute and chronic phases of illness, especially cancer and diabetes. The subscale used for this study consists of twelve items measuring physical symptoms. Each of the items is rated on a 5-point Likert-type scale. The DOII has been used with samples of diabetes and cancer patients and has demonstrated good validity.

The third concept in the model is **ways of coping**, and refers to the ways women act in their relationships while dealing with a stressful event. Two types of relational coping styles were examined: active engagement and protective buffering. Active engagement has been described as a strategy of constructive problem-solving including involving the partner in discussions and inquiring about the partner's feelings. Protective Buffering, on the other hand, is a strategy which involves hiding one's concerns, denying worries, and yielding to one's partner in order to avoid disagreements. Although quite different from each other in some ways, both styles are relational because they involve an awareness of a partner's presence,

potential needs, and reactions. These variables are subscales of a 23-item scale developed by Coyne and Smith (1991) which assesses how an individual manages her or his partner's presence and emotional needs in the context of a stressful situation. Respondents rate items on a 5-point scale. Active engagement is assessed with 11 items including "sit down and have a discussion with a family member" and "try to find out what my family is feeling." Protective buffering is assessed with 12 items including "not disagree with my family" and "try to keep calm." Both subscales have demonstrated acceptable alphas of .90 and .92 respectively with patients.

The final concepts in the model--**quality of life** and **self-care agency**--are outcome variables. Self-care agency refers to a person's evaluation of her agency or power to engage in self-care actions. This variable was measured with the Exercise of Self-Care Agency Scale developed by Kearney and Fleischer (1979). The construct of "exercise of self-care agency" has been described by the instrument developers as a "dispositional trait" which is attitudinal and cannot be measured solely by direct observation. The instrument contains 43 items which measure several subconstructs: (a) an attitude of responsibility for self; (b) motivation to care for self; (c) an application of knowledge to self care; (d) the valuing of health priorities; and (e) high self-esteem. The scale has demonstrated sufficient reliability and validity.

Quality of life was measured with the Functional Assessment of Cancer Therapy Scale (FACT) developed by Cella et al. (1993). The FACT includes 28 generic items which comprise five subscales: physical well-being; social/family well-being; relationship with doctor; emotional well-being; and functional well-being. Respondents rate items on a 5-point scale. Thirteen additional items are specific to common physical and emotional side effects of cancer diagnosis and treatment. The FACT has demonstrated sufficient reliability, validity, and sensitivity to change over time.

Methodology

Data were collected with two instruments--a mailed questionnaire completed by participants at home and an interview schedule which was administered in person. Both instruments were developed by a research team which included me and four other social workers affiliated with the participants' treatment facilities. The questionnaire includes measures of each of the variables in the model. The interview was semi-structured and allowed for greater exploration of the impact of the illness on the primary partnered relationship and support received from the primary partner.

Participants were referred from nursing, medical, and social work staff at two major teaching hospitals in Boston. Participants met the following criteria: a) currently receiving some form of treatment including chemotherapy, radiation, prophylactic antibiotics, or a

combination of treatments for cancer; b) the diagnosis had been made at least two months but not more than two years prior to participation; c) the mother of at least one child twelve years old or younger; and d) currently involved in a primary partnered relationship which was defined as an emotionally significant intimate relationship with a partner of the same or opposite sex.

Results

Forty-eight women participated in the study, reflecting a participation rate of 70%. All participants completed the questionnaire while only forty completed the interview. The average participant was White, Catholic, married, in her thirties, and had one or two children. The women had various types of cancer, the most common forms being breast (48%), Hodgkin's (13%), and leukemia (13%), and were diagnosed an average of 9.7 months prior to participation.

The data revealed no significant relationship between the level of perceived mutuality in the primary partnered and demands of illness ($r = -.11$, N.S.). Subsequently, the first hypothesis was not supported. There are several possible explanations: (a) efforts increased but resulting level of mutuality did not; (b) the correlation between mutuality and demands of illness might reach a level of statistical significance with a later sample; and (c) neither variable influences the other directly. Regardless of the explanation, this finding alone cannot refute the significance of relationship mutuality in the coping process. It may simply indicate that regardless of a woman's physical symptoms and side effects, we cannot assume that she is receiving the support she needs to cope well.

The data showed a significant negative correlation between mutuality and protective buffering ($r = -.47$, $p < .01$) and a negative correlation between mutuality and active engagement ($r = -.11$, N.S.). What makes these data particularly compelling clinically is that protective buffering was also found to be negatively correlated to self-care health behaviors ($r = -.40$, $p < .01$) and quality of life ($r = -.30$, N.S.). This correlation indicates that women who utilize the protective buffering coping style are less likely to perform activities which are essential for their self-care and are less likely to rate high on quality of life. These data suggest that the protective buffering coping style is maladaptive and that women who perceived their primary partnered relationship to be lower in mutuality were more likely to engage in this type of coping behavior.

Significant correlations were found between mutuality and quality of life ($r = .32$, $p < .05$) and between mutuality and self-care agency ($r = .35$, $p < .05$). Stepwise regression was used for multivariate analyses with quality of life (FACT) and self-care agency as the outcome variables, and mutuality, demands of illness, and demographic variables as

predictors. Because of the high correlation between DOII and the FACT ($r = -.37$, $p < .05$), several regressions were run with quality of life (FACT) as the outcome variable. In the first regression, the physical well-being subscale of the FACT was excluded from the scale because of its similarity to the demands of illness scale. The results of this analysis show that mutuality was a significant predictor of both quality of life and self-care agency.

However, because physical well-being is an integral aspect of quality of life for persons coping with medical issues. It is arguable that excluding this subscale from the FACT would affect the integrity of the scale and provide a less than adequate measure of overall quality of life for this sample. Consequently, another way to adjust for the high correlation between the DOII and the FACT was to perform two additional regression analyses with quality of life as the outcome variable: the first with the DOII subscale included with the set of predictors and the second with the DOII subscale excluded from the set of predictors. In the first regression, both demands of illness and mutuality were found to be significant predictor of quality of life, with demands of illness being the most significant. In this analysis, the predictors explained 25% of the variance in quality of life. In the second regression, when demands of illness was removed as a predictor, mutuality remained a significant predictor of quality of life, yet the amount of variance explained by the predictors dropped to 16%. Finally, a third regression was performed, with self-care agency as the outcome. Mutuality was the most significant predictor of self-care agency compared to the demographic variables and demands of illness.

These results indicate that women who perceived their primary partnered relationships to have a higher level of mutuality tended to rate higher on both the FACT and the Exercise of Self-Care Agency Scale than women whose relationships were perceived as less mutual. This means that women whose relationships were higher in mutuality experienced greater levels of well-being both in general and with specific regard to the diagnosis of cancer. Further, these women were more likely to value health priorities, demonstrate a stronger attitude of responsibility and a higher motivation to care for themselves, and a higher level of self-esteem, as measured by Exercise of Self-Care Agency Scale. Subsequently, these results also demonstrated that low levels of mutuality in the primary partnered relationship should be considered a risk factor for poor adaptation to cancer.

These data are consistent with findings reported by Sarna (1993) in her study of quality of life in women with lung cancer. Sarna (1993) also found that (a) quality of life was highly correlated with symptom distress, (b) disruptions in quality of life were not significantly different based on education status, religion, or marital status, and (c) when scores for symptom distress were included as predictors of quality of life in multivariate analysis, the combined variance was increased.

Multiple regression analyses, which included active engagement and protective buffering (as well as mutuality, demands of illness, education, income, and length of illness) as predictor variables for psychosocial outcome revealed that neither style of coping was a significant predictor of quality of life. These data are consistent with a meta-analysis of the

coping and social support literature published since 1980, which revealed that "coping strategies seem to explain no more than roughly 5% of the variation in well-being, whether this is measured in terms of depression (as is often the case in cancer patients), invalidity (rheumatic disorders), compliance (diabetes) or other outcome parameters" (de Ridder & Schreurs, 1996).

Protective buffering, however, was a significant predictor of self-care agency, the relationship between the two variables being negative. This finding further suggests that the use of protective buffering coping strategies has serious implications for women's health as indicated by a decreased tendency to value health priorities and a lower motivation for self-care. These data also appear to be consistent with findings from prior research which indicate that active problem-oriented coping has no more than a slightly positive effect on patient well-being, while coping styles which involve only passive avoidance strategies have a relatively large negative effect on well-being (de Ridder & Schreurs, 1996). Perhaps, as summarized by these authors, the value of coping is seen not so much in increased levels of well-being, but in the prevention of a worse situation (de Ridder & Schreurs, 1996).

Thus, although the data do not show that active engagement coping strategies contribute significantly to increased quality of life or exercise of self-care agency, they do reveal that the use of protective buffering coping strategies is predictive of a decreased motivation for self-care and a decreased tendency to value health priorities in this sample of female cancer patients.

A Path Analysis procedure was used to test the relationships among demands of illness, mutuality, relationship-focused coping strategies, and psychosocial outcome as proposed in the original model. This procedure allows the direct, indirect, and total effects of each independent variable on each dependent variable within a proposed model to be estimated (Tran, Fitzpatrick, Berg, & Wright, in press). The beta weights of each variable (determined by multivariate analysis) provide an index of the impact of each independent variable on each dependent variable when the effects of other independent variables are held constant (Pilcher, 1990). These beta weights are then presented in diagrammatic form. The current path model required four structural equations, each of which consisted of a dependent variable and a set of independent variables.

The general hypothesis tested with this model is that: (a) the level of a woman's cancer demands and the level of perceived mutuality in her primary partnered relationship influences which type of relationship-focused coping strategy (active engagement or protective buffering) she will utilize during her illness experience; (b) the type of relationship-focused coping strategy a woman utilizes will influence her quality of life and her exercise of self-care agency; and © the level of perceived mutuality and the level of cancer demands will influence a woman's quality of life and exercise of self-care agency both directly and indirectly through the type of relationship-focused coping strategy used.

The first equation specifies the effects of mutuality and demands on illness on active engagement, while the second analyzes the effects of these variables on protective buffering. The third and fourth equations specify the effects of mutuality, demands of illness, active engagement, and protective buffering on quality of life and self-care agency. The relationships depicted in the model were presented after controlling for the demographic variables: income, education, and length of illness.

The results of the regression analyses performed for the path analysis indicate that mutuality did not have a significant direct effect on active engagement but did have a significant direct effect on protective buffering. On the contrary, demands of illness had a significant direct effect on active engagement but not on protective buffering. These results suggest that women with lower levels of perceived mutuality in their primary partnered relationships tend to utilize protective buffering coping strategies more than women with higher levels of perceived mutuality ($DE = -.397$). Also, women who experience higher levels of illness demands tend to utilize active engagement coping strategies more than women with lower demands of illness ($DE = .348$).

None of the predictor variables had a significant direct effect on quality of life, and only protective buffering had a significant direct effect on self-care agency ($DE = -.418$). These results suggest that women who utilize protective buffering coping strategies tend to demonstrate less motivation for self-care and a decreased valuing of health priorities. The use of active engagement coping strategies did not have a significant direct effect on either quality of life or self-care agency. Because the subscales of active engagement and protective buffering were so highly correlated, they were collapsed to form one scale of relationship-focused coping which was used as a predictor variable in the regression analyses. It is important to note that this new variable still did not reach a level of statistical significance as a predictor of either quality of life or self-care agency. Yet when this new variable was used as a dependent variable, both mutuality and income level were found to be significant predictors.

In summary, these data support only several of the proposed pathways among the study variables. The level of perceived mutuality appears to have a significant direct effect on the use of protective buffering coping strategies and an indirect negative effect on exercise of self-care agency (via the use of protective buffering). Because of the high correlation between the subscales of active engagement and protective buffering, the process by which women's relationship-focused coping fits into this model warrants further study. Future research could help to further differentiate the subscales and obtain a clearer picture of the circumstances under which women utilize each type of coping strategies. Consequently, although the path model does not provide definitive data, it does suggest that relationship mutuality and the use of protective buffering coping strategies should be assessed as risk factors in women's psychosocial adaptation to cancer.

A content analysis of interview data provides a rich and detailed picture of the nature of the changes experienced in the primary partnered relationship. Some of these changes were

viewed as unwanted losses in the relationship, while others were seen as positive. Participants' descriptions of the changes in their primary partnered relationships fell into five categories: social, sexual, emotional, philosophical, and roles.

The most frequently noted change/impact was in the category labeled emotional changes. Eighty percent of the entire sample ($N=40$) reported an emotional change(s) in their primary partnered relationship. For most of these women (65%), these changes were largely positive, including: being closer and stronger as a couple/family unit; not taking one another for granted; and being more conscientious about resolving problems together. For a smaller but significant number of the participants who reported an emotional change (35%), the changes were described as negative. These changes included: receiving less support from their partners and being aware that their partners were contending with additional stresses which made the partners feel scared, overwhelmed, and helpless.

The next most commonly cited relational impact was a change in the sexual relationship with the primary partner, with thirty-two percent of the entire sample noting such an impact. All participants in this subgroup reported that their frequency of sexual activity had either significantly decreased or ceased completely. While most of the women seemed to miss this sexual intimacy, they seemed hopeful that it would return when they were feeling better physically. Two additional areas in which participants described changes in their primary partnered relationships include family roles and social lives. Thirteen percent of the sample reported the former, and ten percent reported the latter type of impact. Role changes included: participants becoming more dependent on their partners and partners becoming more involved with child care or domestic work. Changes in families' social lives included: less time with friends, less time engaging in leisure activities, and less privacy. Finally, a small percentage (10%) of participants described changes in the philosophical outlook on life that they and their partners held.

Eighty-two percent of participants who were interviewed reported that the amount of support they received from their partners had changed since their diagnosis. Content analysis showed that most participants seemed to feel that they received more support from their partners after the diagnosis, with only a few reporting that they received less. The type of help participants described their partners providing fell into three major categories: instrumental, emotional, and medical.

Instrumental help was an active form of assistance related to the daily activities and logistics of family life (for example, domestic work and child care). Some participants also reported that their partners took care of themselves more and carried out various household and family responsibilities without being asked to do so. These findings support previous work by Coyne & Bolger (1990) who stated "much that is done that is beneficial to the other is a matter of how one attends to one's own coping tasks, rather than a matter of providing support to the other." Coyne & Smith (1991) also stress that patient efficacy in meeting the challenges of a chronic illness is linked with spouses' ability to meet their own challenges.

Emotional help refers to a type of assistance which seemed to rise out of a sensitivity to participants' emotional needs. Examples of such help include talking more; listening more; being optimistic about treatment and the future; soothing the patient; and offering reassurance about the illness and the relationship.

Medical assistance refers to help which was directly related to the participants' medical treatment. It involved activities such as making visits or telephone calls while the patient was in the hospital, accompanying the participant for medical tests and appointments, setting up networks of visitors during hospitalizations, obtaining information about the illness, and helping to manage medications.

Half of the participants (50%) described being very satisfied with the level and type of support that they received from their partners, several noting that their partners had helped even more than they had expected. A slightly smaller group (45%) of participants did not seem quite as positive about the support they received. Nevertheless, they seemed generally satisfied with the amount and type of support they received from their partners and indicated that the support they received was as much as they felt they could expect. Only two participants (5%) described feeling very unsatisfied with their partners' help.

Utility for Social Work Practice

This study has enhanced our understanding of which types of relational activities are most helpful in women's adaptation to cancer and has shed light on the specific mechanisms through which relationships may enhance quality of life and women's exercise of self-care agency. This knowledge can in turn influence our practice in the following ways. First, the findings can be used to assist social workers in screening for high-risk patients (i.e. patients whose relationships are low in mutuality and patients who utilize protective buffering coping strategies). Furthermore, social workers can educate women and their families about how to increase or establish relationship mutuality either with primary partners or others and can help them to develop coping strategies other than protective buffering.

The findings of this study can also be used to educate physicians and other health care professionals who have power and influence in developing programs and treatment plans which affect women with cancer. Poor psychosocial adaptation can be manifested in a number of ways which economically influence hospitals and other health care organizations (examples are increased calls to medical staff, delayed discharges, and increased use of psychotropic medications or psychiatric hospitalizations). These findings can lead to proactive screening and intervention which could help to minimize inefficiencies within the medical system.

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